WHY INTEGRATION?

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1. <u>Segregated services cannot</u> be <u>habilitative</u>

It has been many years now since Burton Blatt published Christmas in Purgatory (1966) and Souls in Extremis (1973)—books which were both reflections of and generated further public and professional concern about the abuses that seemed to be widespead in American's institutions for persons with mental retardation. Yet, despite almost universal "best intentions" accompanied by a massive infusion of millions upon millions of dollars to reform and even rebuild these institutions throughout the country, they remain grossly substandard. Both Pennhurst in Pennsylvania and Willowbrook in New York stand as examples of institutions that seemed incapable of becoming habilitative living and training environments no matter how sincere the effort nor how large the investment of public funds to change them.

Segregated schools and large "group homes" which have become the gathering place for only persons with disabilities—often only those with the most severe disabilities—and the professionals and volunteers who are paid to care for and teach them are similarly problematic. With no models of what life should be like and what nonhandicapped persons do at different ages and in typical environments, these environments more closely resemble small institutions than they do families and regular schools. How can a group of 6-10 children with autism—so diagnosed because they don't socially interact and because they have certain bizarre behaviors such as stereotyped hand movements and perhaps even disruptive and other problem behaviors—provide the individual students in that classroom with the models and with peers who are able to encourage and support new, positive social behaviors? Will these children truly learn only from the paid professionals who attempt to teach them new skills, or will they also learn from the other students around them? How can persons placed "randomly" or admininstratively into group homes without regard for their social relationships but based only upon openings and diagnostic groupings be lucky enough to somehow find a friend among these assigned housemates?

Do institutions and homogeneously grouped places and programs work? Or do they by their very nature become increasingly deviant and discrepant from the mainstream of society, so that no one except paid staff will go there—except for episodic gestures by volunteer organizations which seem motivated by "kindness" and "caring for the handicapped" rather than by respect for the dignity and worth of every individual? Would you live in an institution? Would you allow yourself to be randomly placed in a group home for the rest of your life? Would you want to attend school only with other people who, like you,

happen to share one particular characteristic such as being extremely shy or having difficulties with mathematics? These are, of course, silly examples, but it seems no less silly to "group" people together simply because they all have mental retardation or all have autism than to group them together because they all share an Italian heritage. We may indeed share times and experiences with persons who resemble ourselves for some activities and even for shared educational needs. But all of the time? And with no opportunities for other experiences and other interactions?

If millions of dollars and more than two decades of significant efforts at institutional reform have failed to eliminate the continued charges of abuse and meaningless activities for the persons who live in such places, is it not time to acknowledge that perhaps it is impossible to make these environments habilitative? We have tried long enough. As Lou Brown recently wrote: "The segregationists did their best, but they have not done the job. They had their day, now they must step aside."

2.   Integration is a civil right

The history of separate services reflects exclusion of persons from the community, from particular programs, and from normalized patterns of daily living. This exclusion has been justified because persons with disabilities were said to be somehow "different" from the mainstream of society. Although the rationale of "separate but equal" is often articulated and handicapped-only schools are even sometimes described as being "enriched and specialized," the reality is that handicapped children have historically settled for separate programs which do not offer the full range of opportunities available to most children in regular public schools.

Handicapped-only schools were once the result of a long history of gaining some services for children with disabilities where once there were no services. Their origin is often one of extensive fund-raising (appealing to charity and "giving" by others to the "less fortunate") and advocacy (arguing that persons with disabilities also have a right to go to school) to support a special place. Since local educational agencies and the local public school were not willing to enroll children with severe disabilities in their programs, it was natural that the easiest way to obtain services was to set up something separate. And, of course, separate schools do not in any way threaten the "way things are" in the regular school.

But even if the separate, handicapped-only school does offer specialized services to meet the needs of the students who attend the program, this compromise to the right to associate with nonhandicapped peers is neither justified nor is it necessary. As Gilhool and Stutman (1979) stated:

There is no cognizable reasons under the statutes for handicapped-only centers, certainly not on the scale they now exist. If a child can come to a school at all, even to a self-contained class in a handicapped-only center, he can come to a self-contained class in a normal school. Any teaching technique that can be used in a self-contained class can be used in a regular school building. There are few if any legitimate teaching strategies which require the complete isolation of a child from interaction with other children, and the few such strategies that there may be apply to very few children and for very short periods of time (p. 215).

It is now time for us to acknowledge that our children and students have as much right to attend their neighborhood public school—and receive individually appropriate services in that school—as other children do. There should be "room" for us, just as there is room for the fourth graders who are not handicapped. We should not have to trade off the right to have our children attend school with other children who do not have disabilities in order to obtain appropriate educational programs—anymore than the parents of a fourth grader would be told that "I'm sorry, but your neighborhood public school doesn't have space for fourth grade this year. If you are willing to put him in third (or fifth) grade, he might be able to go here. Otherwise, a special bus for fourth graders will pick him up for an hour ride to a special school in another part of the city."

3. Integration is cost-effective

There is much evidence that it is less expensive to provide the same quality of services in an integrated, community-based program as to provide those services in a handicapped-only setting. The logical reason for this is that in regular programs, the various building, aldministrative, and ancillary program costs are part of the overall budget. Expensive transportation costs would also be largely unnecessary as children with disabilities ride the same busses (at least some of which would have to be accessible) their peers ride, to go to the same school a much shorter distance away.

In handicapped-only settings, duplicate facilities and services must be specially budgeted and staffed. Thus, in institutions, there is typically a special dentist and doctor for persons with disabilities, a handicapped-only laundry room, a security staff, principals and ward supervisors, and superintendents of the state hospital. Institutions and even special schools often have their own swimming pools and bowling alleys—some institutions even include mini-shopping malls within their buildings. In community-based programs, only direct care staff costs (such as program coordinators,   teachers,   and

assistants) are charged to the special program, and networks of informal, community supports as well as access to existing community services (nonhandicapped co-workers, the municipal police force, existing recreation programs, principals of the regular school, the community librarian, physicians and dentists, and so forth) are costs which the mainstream supports for everyone.

Of course, cost-effectiveness is not the best programmatic or ethical reason to do something, and the historical risk is that if we argue cost-effectiveness too strongly, needed programs and individual supports will be withdrawn from budgets. Movement of programs into the community does not mean that persons with severe disabilities do not need support on a continuing basis. In fact, what is needed is that the same kinds of services and supports so readily available only in segregated settings must now be transferred to families, schools, neighborhoods, and other community settings. If we overstate our case and funds are significantly reduced, we may find ourselves once again the position of approaching agencies, legislatures, and the public to ask for special appropriations for services and programs. And, from the perspective of wanting what is best for our children and as professionals and advocates who want to use the most effective (not the cheapest!) strategies, there should be a limit as to how much emphasis we are willing to put on this argument (Voeltz & Evans, 1983).

There are powerful programmatic reasons to support integration—which just happens to be the most effective as we shall discuss next. But, it is also true that cost-effectiveness is a reality, and can be a persuasive argument to obtain support for the integration of persons with disabilities into society.

Why, for example, do we continue to pay approximately $55,000 yearly to "care for" a person with mental retardation in an institution when we know that quality community-based programs will cost half that amount? Why do we continue to allow our districts and states to contract for special schools at costs greater than $100,000 per pupil each year, when other districts are able to serve students with similar needs at less than one-fifth this cost? And ask yourself: What could you as a parent or program administrator do on behalf of that same handicapped individual if someone were to provide you with even half of the cost now charged for institutions and segregated schools?

4. Integration is necessary for curricular reasons

If children with disabilities are to acquire the skills and behaviors they will need to function in the "real world," they must be instructed in the various environments which are part of that reality, and they must learn to interact with the many persons (handicapped and nonhandicapped) who live, work, and recreate in those environments.

As long as children with disabilities spend all of their time in segregated schools, the only interactions they will have are with teachers, therapists, educational assistants, and their parents. They are missing out on the variety of opportunities to learn and to practice what they are learning through daily interactions with their nondisabled peers and other persons in the community who do not have handicaps. We recognize that peer interactions are valuable learning experiences for children, and there is a rich child development literature that talks about the value of these peer relationships and play with others. These "less formal[11] interactions are the context for practicing skills that might be learned from a teacher or parent. For example, it is difficult to imagine how a child would actually learn to talk if all language opportunities were restricted to "language therapy" with a teacher and speech therapist. Children's games provide many opportunities to practice motor skills, language skills, dressing and undressing to go outside to play, swim, and so forth.

Not only do peer interactions give children comfortable and fun opportunities to practice skills, there are some skills that can only be learned in the context of these interactions. How can a teacher or parent really teach play and social behaviors and skills? Nonhandicapped children do not learn these things in fourth grade from their teachers, and there is a great deal of evidence that it is the peer group which teaches rules and behavior. Knowing how to appropriately interact with other people and knowing how to "play" are essential adaptation skills. Our children need the opportunity to develop these skills.

Finally, our past failures in teaching skills that generalize to the relevant situations and maintain across time have led us to reconsider past instructional practices. It appears that skills learned in an artificial or simulated setting and taught in isolation from one another will have limited usefulness. We can teach a new skill in the classroom, but if we want the child to use that skill somewhere else—at home, in a shopping center, at a restaurant, and so forth—we must start all over again and teach it in that location. And we can teach a particular motor behavior and a language behavior separately—one taught by the occupational therapist and the other by the speech therapist—but if we want the child to use them together as part of a natural activity sequence, it appears that we have to teach the behaviors again in the context of the activity.

In fact, the more severe the child's learning problems, the less likely it is that he or she will be able to take abstract and simulated and isolated instruction and apply it or "generalize" new skills to the real world. Since the ultimate goal of nearly everything we teach is to establish a meaningful, functional skill, why not simply put our instructional efforts into teaching what and where we really want the new behavior to

occur? If this is to, happen, we must begin teaching in the context of criterion environments —school and community alike (Brown, Nietupski, & Hamre-Nietups)ci, 1976).

5. Integration is needed to create congruent (supportive) environments

For many years now, independence has been our goal. This emphasis upon preparing the individual person with disabilities for independence was probably not realistic, but more importantly, It is not even normalized. Very few of us are independent: We are, each of us, part of a variety of complex, mutually beneficial "support networks" at home, school, work, and in the community. We negotiate complementary roles at home in our family: There are some things that each person in the household can or cannot do and/or dislikes doing less than someone else, so "jobs" are divided up accordingly. Family members take on responsibilities that reflect personal needs, interests, and strengths, as well as the needs of the household. Other things are not done by anyone in the family: We usually hire someone to fix our plumbing, car, refrigerator, furnace, and even clean our laundry and shovel our sidewalks if we can.

At work, we very seldom function in homogeneous groupings of people in which everyone works side-by-side doing the same thing at the same level of skill. Instead, work environments are heterogeneous places, with different roles and responsibilities assigned to different people who work together to accomplish a shared goal. In schools, for ex ample, we can find an administrator, teachers, speech therapists, custodians, cafeteria workers, librarians, street crossing guards, and other professionals all at work doing different things to contribute to providing an education to the students in the program.

Why then do we continue to group handicapped persons homogeneously, expecting either the individual persons with disabilities to be independent or a group of persons with disabilities to be independent?

The crucial point is this: Typical environmen ts are characterized by interdependence. If our goal is to prepare persons with disabilities for typical environments, we can no longer avoid our obligation to prepare nonhandicapped persons to include persons with disabilities in these already heterogeneous environments. If we follow the rule of "natural proportion" and do not expect typical environments to absorb unnaturally large groupings of persons with disabilities, it would be simple enough for these environments to include one or more persons with disabilities in settings and activities along with everyone else. But our worries about the ability of existing environments to accept our children should tell us that the time to begin is now.

Only if our children have grown up together, seen one

another in every conceivable context just as nonhandicapped persona now do, and been given daily and nonextraordinary opportunities to become familiar with one another, will today's young people graduate to an adult world which consists of accepting communities with the skills and attitudes needed to support and include persons with severe disabilities. How can a nonhandicapped employer be expected to understand the idiosyncratic stereotyped behavior and the communication board system of a potential employee if he or she has never before interacted with an individual with severe handicaps? Wouldn't "help" natural and readily available to someone with mental retardation who might be confused at a bus stop if the nonhandicapped persons at that street corner were familiar with his or her activity pattern and able to communicate with him or her?

Nonhandicapped persons will not learn to be accepting and supportive by reading books and attending lectures about acceptance and support. They too need to develop and practice the skills to interact constructively with persons with disabilities by doing so with those persons across the lifespan. An awareness that persons with disabilities are indeed persons and acceptance of them as neighbors, acquaintances, co-workers, customers, relatives, and friends will come about through daily experiences—abstract ideas, episodic volunteer activities, and televised appeals for charitable support for programs for "the handicapped" are a poor substitute. We cannot prepare for integration through segregation...

6. Integration is crucial for quality of life

Ask yourself: What would my own life be like if my only interactions with other persons were with my teacher, therapist, and parents? Would I be willing to give up the variety of acquaintances and friendships which have continuously been available to me across my lifetime?

Without exposure to peers, the social interactions of persons with disabilities are all verticle, with an authority figure (a teacher, a mom, and so forth) enforcing conditions to which the child must respond. No matter how kindly this is done and regardless of whether it is in the child's "best interests," the reality is that these individuals are always being acted upon and have little control over their own lives. Even when interactions with parents and paid professionals are indeed nurturant—though even then the child receives, rather than gives, nurturance—many if not most are demand situations, with the child following someone else's guidance and instructions.

Older-child, younger-child friendships often develop between nonhandicapped children in their neighborhoods and between siblings. Studies of these interactions suggest that they are beneficial relationships for both children involved: The younger

child has access to a model who is perhaps less rigid (though the "rules" are also slightly different) than a caregiver and whose modeled patterns of behavior are a bit closer to the younger child's abilities than those of the (more skillful) adult. The older child may also enjoy the respite from the demands of caregivers, same-age peers, and increasingly complex environments, and probably feels a sense of importance and increased self-esteem from playing "big brother/big sister" to a younger person. These cross-age friendships are much like the kind of relationships that seem to develop between same-age friends, one of whom is nondisabled and the other having a severe disability. The benefits appear to be similar, and clearly motivating to the two children to seek out and continue their friendship (Strully & Strully, 1985).

Horizontal interactions with peers offer experiences that differ from the caregiver-child relationships now available to children with disabilities. In horizontal friendship interactions, the child with disabilities is involved in a mutual relationship. We can argue that these interactions also occur between two children with disabilities—and indeed they should—but the reality of the situation is that the more severe the child's disabilities, the more difficult it will be for him or her to access such interactions. A child with sensory and motoric impairments has limited access to spontaneous social interactions unless someone else makes the arrangements. Nonhandicapped children—in addition to less-handicapped and other handicapped peers—can extend the social opportunities of our children dramatically, and they do.

Interactions with others enrich our lives and give us the chance to develop friendships and critical personal relationships which we will enjoy across our lifespan. We typically regard these interactions, relationships, and friendships as central to our personal well-being. It is time for children with disabilities to share these experiences, so that these individuals will no longer be isolated from what is perhaps the most essential component of what we elusively refer to as "quality of life."

April 1987

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Note: An earlier version of this paper was presented to a group of parents in Philadelphia, Pennsylvania, in November 1983.

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